

The Psychology of Survivorship: Understand, Assess, Intervene, Refer

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Cancer Survivors and Survivorship Care
Providing High-Quality Care
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*Understanding human
needs is half the job of
meeting them*

– Adlai Stevenson



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Assumption about Cancer

- Has critical attributes of a traumatic life event (chronic extreme stressor)
- Characterized by loss and crisis
- Patients think continuously about what might happen
- Cancer is not one event, it is a process
- Cancer's impact is individual
- Journey does not end when treatment ends



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Factors Affecting Cancer Experience

- Age/Developmental stage
- Work status
- Social/familial support
- Quality of partnered relationship
- Access to health care
- Psychological/Psychiatric history
- Co-morbid disease



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Developmental Phase of Individual: Diagnosis & Survivorship

- Childhood before 12
- Adolescence 13-18
- Young Adulthood 18 - 25
- Child-rearing 25 - 50
- Post- Menopausal Middle Age 50 - 60
- Pre-Retirement 60 - 70
- Retirement 70 - 90



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Vignette: Early 20, lymphoma, 10 year survivor

- Scholar, preparing for graduate school, successful in sports
- Still thinking about graduate school
- Successful in work endeavors
- Not married, no relationships, not dating
- Refers to men as “boys”
- Cancer like a pause button, never restarted play
- Currently experiencing increasing panic attacks and fears of something bad happening



Disrupts Psychological Well-being

- Anxiety & depression
 - Worry
 - Sadness
- Post-traumatic stress disorder
- Loss of control, self-esteem and mastery
- Uncertainty and vulnerability
 - Fear of Recurrence
 - Fear of future
 - Death anxiety
 - Late Effects



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Psychological Distress

- Variability in studies
 - Summaries suggest emotional QoL & psychosocial adjustment are good
 - Rates of psychiatric disorders and clinical levels of distress low 15%
 - Improvements in first two years after treatment
 - By 5 years similar or lower to normal population



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Psychological Distress

- Individual differences exist
- Psychological distress higher
 - in poor prognoses
 - in those receiving more aversive treatment
- Ovarian and Testicular Cancers
 - High anxiety, low depression
- Head & Neck Patients
 - Anxiety and depression



Psychological Distress Stem Cell Transplant (80% Leukemia/Lymphoma)

- Average 3.4 years post transplant
- No differences between
 - < 3 years
 - 3-6 years
 - 6 or more years post transplant
- No difference in age, gender, time since transplant or transplant type
- Global Distress 43%
- 1 in 4 had clinically significant depression & anxiety



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Psychological Distress Stem Cell Transplant (80% Leukemia/Lymphoma)

- Looked similar to newly diagnosed sample
- Loneliness and isolation suggesting greater existential crisis



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Psychological Distress

- Limitations
 - What psychological variables are being assessed
 - Many studies on breast cancer only
 - Individual differences and specific concerns
- Cannot assume that distress levels are normal without assessing



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Fear of Recurrence

- **Prevalent in Cancer Survivors**

- Kornblith, Herndon, Zuckerman et al. Comparison of psychosocial adaptation of advanced stage Hodgkin's disease and acute leukemia survivors. *Ann Oncol*, 9, 1998.

- **Ranges 5%-89%**

- Ronson, Body. Psychosocial rehabilitation of cancer patients after curative therapy. *Support Care Cancer* 10, 2002.

- **Described as largest concern of breast cancer patients**

- Spencer, Lehman, Wynings, et al. Concerns about breast cancer and relations to psychosocial well-being in a multiethnic sample of early stage patients. *Health Psychol* 18, 1999.

- **Persists at least up to 9 years post TX**

- Mishel, Germino, Gil et al. Benefits from an uncertainty management intervention for African-American and Caucasian older long-term breast cancer survivors. *Psychooncology* 14, 2005.



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Life is Good, But Fear Persists

- Art Task: Illustrate how you are feeling today.
- Description: Tissue paper collage, 18 x 24 inches.
- Life is good after completing treatment and the tree is strong. But there are still dark clouds hovering overhead and those annoying blackbirds.



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Fear of Recurrence – H & N Cancers

- Not related to:
 - Disease related variables
 - Sociodemographic variables
 - Symptoms
- Related to:
 - Anxiety
 - Pre-treatment fears
 - Low levels of optimism
 - PTSD
- 1/3 reported fear often or all of the time



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Fear of Recurrence

- “How often have you worried about the possibility that the cancer might come back?”
 - None of the time
 - Rarely
 - Occasionally
 - Often
 - All of the time
- Fears diminish but Fear of Recurrence may be stable



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Post Traumatic Stress Disorder (PTSD)

- Intense fear, helplessness or horrors resulting from an extreme traumatic stressor
- Symptoms fall into three clusters
 - (DSM-IV)



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Post Traumatic Stress Disorder (PTSD)

- **Reexperiencing Symptoms** – relives trauma, flashbacks, memories, uncontrollable thoughts feelings images (**intrusive thoughts & memories most common**)
- **Avoidance** -- of situations that bring back memories of event (may get detachment and emotional numbness)
- **Hyperarousal** -- usually as consequence to trigger includes insomnia, irritability, increased psychophysiological arousal decrease in concentration alertness, startle response



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Post Traumatic Stress Disorder (PTSD)

- Prevalence in Cancer – Approximately 10-15%
 - range in studies is 0-60% depending on how measured
 - PTSS (Post Traumatic Stress Symptom)
- Reexperiencing symptoms 36-72%
 - intrusive thoughts and memories most common
- Hyperarousal symptoms 11-27%
- Avoidance symptoms 7-80%
- Prevalence in general adult population = 2.4%



Breast CA and PTSD....

- Diagnosed twice as long
- Similar age
- Lower quality of life
- Lower spiritual well-being
- Great emotional distress
- Felt more helpless/hopeless
- Anxious preoccupations with illness
- Felt less sexually attractive
- Worried more about the effects of stress on illness



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Transplant Survivors & PTSD

- PTSD Symptoms & Depression symptoms overlap
 - Difficulty falling asleep or staying asleep
 - Difficulty concentrating
 - Diminished interest
- Global Distress 43.2% when PTSD sample eliminated
36.7%



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NHL Survivors (M=10.4 years) PTSD

- 7 % met full criteria of all three clusters
- 17% met at least two criteria
- 39% met one symptom cluster
- Results similar in survivors with and without active disease
- Higher in nonwhite and less educated
- Younger more likely to develop PTSD
- Low social support more PTSD



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PTSD & Fear of Recurrence

- Is there a link between fear of recurrence and PTSD?
- Likely, demonstrated in H & N patients
- Cancer-related PTSD differs from more traditional traumas in that the intrusions tend to be future-oriented fears such as concerning recurrence or treatment.



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Individual Characteristics

- The extent to which there are ongoing emotional or psychosocial difficulties depends on the degree of disturbance in
 - Life roles
 - Goals
 - Expectations
- Younger age predicts emotional fallout
 - More anxiety and depression
 - More distress about cancer reminders
 - More stressful appraisals of cancer
 - Lower health related quality of life



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Benefits (Post -Traumatic Growth)

- “Growth”
 - Individual undergoes a stage in their personal development that extends beyond their previous functioning



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Benefits (Post -Traumatic Growth)

- Perceived changes in self
 - Feeling stronger
 - More self assured
 - More experienced
 - More able to face future challenges



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Benefits (Post -Traumatic Growth)

- Changes in interpersonal relationships
 - Ties with other people are strengthened
 - The need to share and express one's feelings increase
- Changes in spirituality or the philosophy of life
 - Greater appreciation of what one has
 - Becoming easier for the individual to distinguish what is really important from what is of secondary importance
 - Change in their scale of values

(Tedeschi, Park, Calhoun, 1998)



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Benefits – The Yellow Brick Road

- 92 women
- Post-treatment breast cancer
- 83% identified benefit
- 2.6 Mean benefits in the following categories
 - 46% Relating to others
 - 13% Health-related benefits
 - 12% Appreciation of life
 - 11% New possibilities
 - 9% Personal strength/growth
 - 6% Spirituality



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Sears SR, Stanton AL, Danoff-Burg S. The Yellow Brick Road and the Emerald City: Benefit Finding, Positive Reappraisal Coping, and Posttraumatic Growth in Women with Early Stage Breast Cancer, 2003, 22:487-497.

Assumptions from Literature

- Cancer has potential for marked **psychological distress** and **life disruption**
- Rates of psychological disorder exceeds those of general population
- For most individuals, distress remits (24 months) **if no recurrence**
- Effect on QOL is uneven across persons
- Many find benefit and meaning in experience



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Assumptions from Literature - Continued

- Many survivors have unmet needs that can be persistent -- psychological and physical decrements in function.

Protective

- Emotionally supportive relationships
- Use of active coping strategies such as problem solving, positive reappraisal, and emotional expression

Risks

- Chemotherapy
- Social isolation or conflict
- Expectancies for low control and negative outcomes
- Attempts to avoid thoughts and feelings surrounding cancer



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Health Providers Roles in Facilitating Psychological Well-Being



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Communication

- Physician often fail to ask about psychosocial/emotional issues
- Patients are reluctant to bring up psychosocial/emotional issues unless asked
- Patients value being asked about how they are doing emotionally
- Creates a patient centered approach
- Physician words/tone/body language are **EXTREMELY POWERFUL**
- Choose words wisely, attend to tone and style



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What to ask?

- Tell me about how your life has changed since your cancer diagnosis
- How are your moods?
 - Are there times you experience anxiety or worry?
 - Sadness, feeling blue?
- Do you have difficulty getting to sleep?
 - Staying asleep
 - Waking often
- Have you noticed any difficulties with concentration?



What to ask?

- What is it like for you to come back to the doctor for check-ups related to your cancer?
- How often do you worry about cancer coming back?
- Have you noticed any positive changes in your life since the diagnosis?



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Making Normative Statements

- Many of my patients, regardless of prognosis worry about recurrence
- Some people continue to experience anxiety/depression after the treatment has ended
- Sometimes people benefit from having someone to talk to in more depth about the impact that cancer has had on your life.
- Sometimes when people have to come back to the medical environment it brings up memories of the treatment and this can create a variety of feelings.



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Helping Survivors Manage Fear of Recurrence



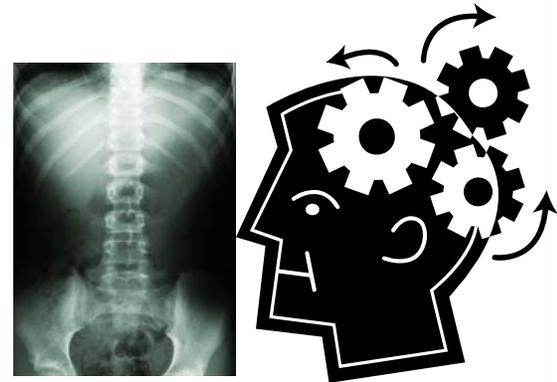
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The Survivors Challenge: Does Cancer Still Exist?

- In body?
- In mind?



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Cancer as Foreground, Cancer as Background

- As patients move into survivorship, cancer moves to background except . . .
 - Aches and pains
 - Scans and doctor visits
 - Anniversaries
 - Friends/families diagnosed or recur
 - Media



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“Someone likened cancer to a pink elephant, and the pink elephant initially is right there in front of your face, you know... and then as you get better, the pink elephant maybe goes to another room. And then as you get much better, the pink elephant goes down the street, but it’s always there and you always know it’s there. And, I think that , as you approach appointments, the pink elephant [from] down the street, you know, comes in the living room again.”



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Development of Individualized Plan to Manage Symptoms/Fear

- Strategies for support from families and friends
- Discussion with physician about handling worrisome symptoms or concerns
 - Comfortable Time Frame
- Development of Cognitive Coping Strategies
- Development of Distraction Techniques
- The Wise Mind
- Avoidance of Internet Surfing



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Plan – Self Talk

- It is unlikely that this is cancer.
- I was screened ____ months ago and things were fine.
- If I have this in two weeks I will go to my doctor.
- I can always go to my doctor sooner if I need reassurance.
- There are 10.5 million cancer survivors, I am one of them.
- I have a lot of inner resources.
- I have people that I can rely on.
- I have a doctor that I can count on to help me with this.
- I can call my friends, who always helps me to feel better.
- I'm going to stop thinking about this, until two weeks have passed.
- I'm going to do something that I enjoy.
- I'm going to write this all down in my journal and leave it.



Help Survivors Develop -- Self Talk

- Give them statements that they can quote to themselves as reassurance
- If we are not detecting cancer then there is no cancer
- If you are worrying a lot, come in and we can assess your symptoms
- You are unlikely to see this cancer again
- The statistics don't matter, you either have cancer or you don't. Right now, you don't have active cancer.
- Fear is a normal part of this process, but it can be managed.



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Refer – Patients Listen to Physicians

- You can't do everything!
- Refer to the Vita Program
- Refer to psychologists
- Refer to the Simms/Mann Center
- “You might benefit from a few sessions with a psychologist who can help you develop a plan to manage fear of recurrence. I recommend this often to help people live more comfortably with uncertainty.”
- “I want all of my patients to go to the survivorship Center at UCLA for one visit to develop a care plan.”



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Services Available at Simms/Mann – UCLA Center for Integrative Oncology

- Psychological Support and Counseling
- Mind/body Techniques
- Groups
 - Psychological and Integrative
- Psychiatry Services for Medication Evaluation
- Integrative Medicine Assessments with Integrative Medicine Physician
 - Diet and Dietary Supplements
 - CAM
 - Bioelectrical Impedance for Lean body Mass



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Services Available at Simms/Mann – UCLA Center for Integrative Oncology

- Reflections Boutique
 - Wigs, hats, scarves, lymphedema garments
 - Physician selected dietary supplements and nutritional supports
- Spiritual care/support
- Lecture Series – Insights Into Cancer
 - See Specific brochure
- Referrals to Resources
- Newsletter
- www.SimmsMannCenter.ucla.edu



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OPTIMIZING WELLNESS | FROM THE DIRECTOR

An honor of my name I have changed the name of our Center from the Ted Stone Family Research Center to the Simms/Mann - UCLA Center for Integrative Oncology in order to better reflect our vision and expanding services. Our new mission:

A center of integrative oncology... maintaining wellness, maximizing health, and complementing the best oncologic practices and scientific research through individualized care offered by a multidisciplinary team committed to enhancing the physical, psychological and spiritual well-being of people touched by cancer.

We believe the broadest statement encompasses the range of aging and new cancer-related challenges. We also believe that the best care is one that is patient and family centered. We also believe that the best care is one that is holistic and addresses the physical, psychological and spiritual well-being of people touched by cancer. We believe that the best care is one that is patient and family centered. We also believe that the best care is one that is holistic and addresses the physical, psychological and spiritual well-being of people touched by cancer.



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Three Wishes

- Cancer could be prevented
- Cancer could be cured for everyone
- Cancer patients and their families receive optimal integrated medical, psychosocial, & psychiatric care throughout the continuum of cancer treatment and survivorship
 - Simms/Mann -- UCLA Center for Integrative Oncology



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Thanks to the
**Wallis Annenberg Director's Initiative
in Psychosocial Oncology**
The Annenberg Foundation
for

*Supporting the leadership of the Center
in direct services, training and educational
programs to improve quality of life for patients with
cancer and their family members*



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**Thanks to the
Simms/Mann Family Foundation
for**

*their continued support and
recognition of the needs of patients
with cancer and their family
members*



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Dedicated to
TED MANN



Former Chairman Mann Theatres

His dedication, compassion & commitment

started the Center



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